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Research

Patient experiences of cancer care: scoping review, future directions, and introduction of a new data resource: Surveillance Epidemiology and End Results-Consumer Assessment of Healthcare Providers and Systems (SEER-CAHPS)

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Abstract

The shift towards providing high value cancer care has placed increasing importance on patient experiences. This scoping review summarizes patient experience literature, highlights research gaps, and provides future research directions. We then introduce a new resource that links the National Cancer Institute's Surveillance Epidemiology and End Results (SEER) program with the Centers for Medicare and Medicaid Services Consumer Assessment of Healthcare Providers and Systems (CAHPS) survey and longitudinal medical claims data. We conducted a scoping review to identify relevant research within the Medicare CAHPS domain that examine factors associated with patient-reported experiences with their cancer care. Gaps indicate a need for population-based research to explore relationships between cancer patient experiences, healthcare utilization, and subsequent patient outcomes. SEER-CAHPS, a publicly accessible data resource, may assist in addressing these gaps by linking cancer registry (SEER), survey data reported by Medicare beneficiaries (CAHPS), and Medicare claims, providing unique insight into quality of care. Linked data include 231,089 surveys from patients with a cancer diagnosis, and 4,236,529 surveys from patients without a cancer diagnosis. Results indicate substantial gaps in our knowledge of patient experiences and the need for additional resources. SEER-CAHPS links direct patient feedback with cancer registry and Medicare claims, making it an important source of information on experiences and healthcare utilization. Increasing recognition of the importance of patient-centeredness points to the need for population-based studies. Findings from SEER-CAHPS will inform initiatives to improve care delivery.

Keywords

Patient experience, patient-centered care, cancer care, quality of care

Note

Additional information on SEER-CAHPS can be found at http://healthcaredelivery.cancer.gov/seer-cahps/

Introduction

There are an estimated 15.5 million cancer survivors in the United States, and this number is projected to increase to almost 26.1 million by 2024, including 73% of survivors older than the age of 65 [1]. While advances in diagnostic and treatment capabilities have greatly increased survival for many cancers, increasing attention is needed on the experiences of cancer patients, both during and after treatment. The Triple Aim outlines three interdependent goals for improving the quality of the U.S. healthcare system: improving health outcomes, reducing healthcare costs, and improving the experience of care [2].

The focus on patient experience has accompanied a shift in clinical practice toward a model of patient-centered cancer care delivery [3, 4]. While there are varied definitions, Wolf and colleagues [3] posit that "patient experience" captures a more specific measurement of patient care than satisfaction, and Price and colleagues [5] add that patient experiences can refer to any observable process, both subjective or objective, reflecting specific components of care from the patient's perspective. Experience also includes the complex relationship of patient knowledge, values, and expectations of care. Research has noted several challenges in relying exclusively on patient satisfaction as a metric for quality, most notable that it is often influenced by proximal, unrelated outcomes[6-8]

While research has indicated the importance of patient experience, there is a need for an in–depth examination of the literature to define gaps in understanding specific to cancer care. While we acknowledge that there are multiple ways to review a scientific area, we chose to conduct a scoping review, which allows identification of the extent, nature, and range of a given research area, as well as existing gaps. In contrast with systematic reviews, scoping reviews focus more on describing a broader research area rather than providing a synthesis on a narrower scientific topic.

Saunders and colleagues [9] performed a comprehensive review of cancer patient experience measures. While our scoping review is informed by this work, we chose to focus on core domains of patient experiences reflected in the Medicare CAHPS surveys, which were not included in the prior review. These domains include doctor/patient communication, coordination of care, getting needed care and getting care quickly (grouped as access to care for the current paper), quality of care/provider, quality of health plan, prescription drug plan customer service, and getting needed prescription drugs. The purpose of this study was to explore these key components of cancer patient experiences, including the identification of gaps and potential future research questions that could be answered using new data resources. We conclude with the introduction of a new resource that links the National Cancer Institute's Surveillance Epidemiology and End Results (SEER) program with the Centers for Medicare and Medicaid Services Consumer Assessment of Healthcare Providers and Systems (CAHPS®) survey and longitudinal claims data.

Approach and Methods

We used the scoping methodology proposed by Arksey and O'Malley,[10] with additional attention to recommendations from Levac and colleagues [11]. The 6 steps of a scoping review have been outlined as: (1) identify a clear research question; (2) search for relevant studies; (3) select studies; (4) chart the data; (5) collate, summarize, and report results; and (6) consult with stakeholders to contextualize and inform overall findings. Unlike systematic reviews, scoping reviews do not provide a standardized quality assessment of studies. Instead, scoping reviews typically include a summary of exemplary papers and identify areas for future research.

We used PubMed and CINAHL to search the literature for studies published between 2005 and 2016, focusing on cancer patient experiences with care using the term cancer (or neoplasm) in combination with search terms found in Figure 1. The research team developed search terms *a priori* to reflect both core concepts cited in the patient experiences literature and a focus on domains included in the Medicare CAHPS surveys. We refined terms as needed using an iterative process.

Figure 1. Search Terms Used in Combination with Cancer (Neoplasm)[1]

Patient experience
Satisfaction
Communication
Physician communication
Patient provider communication
Getting care quickly
Treatment delay
Timeliness
Access to care
Getting needed care
Quality of care
Quality
Health plan
Health insurance
Prescription drug plan
Medication
Customer service

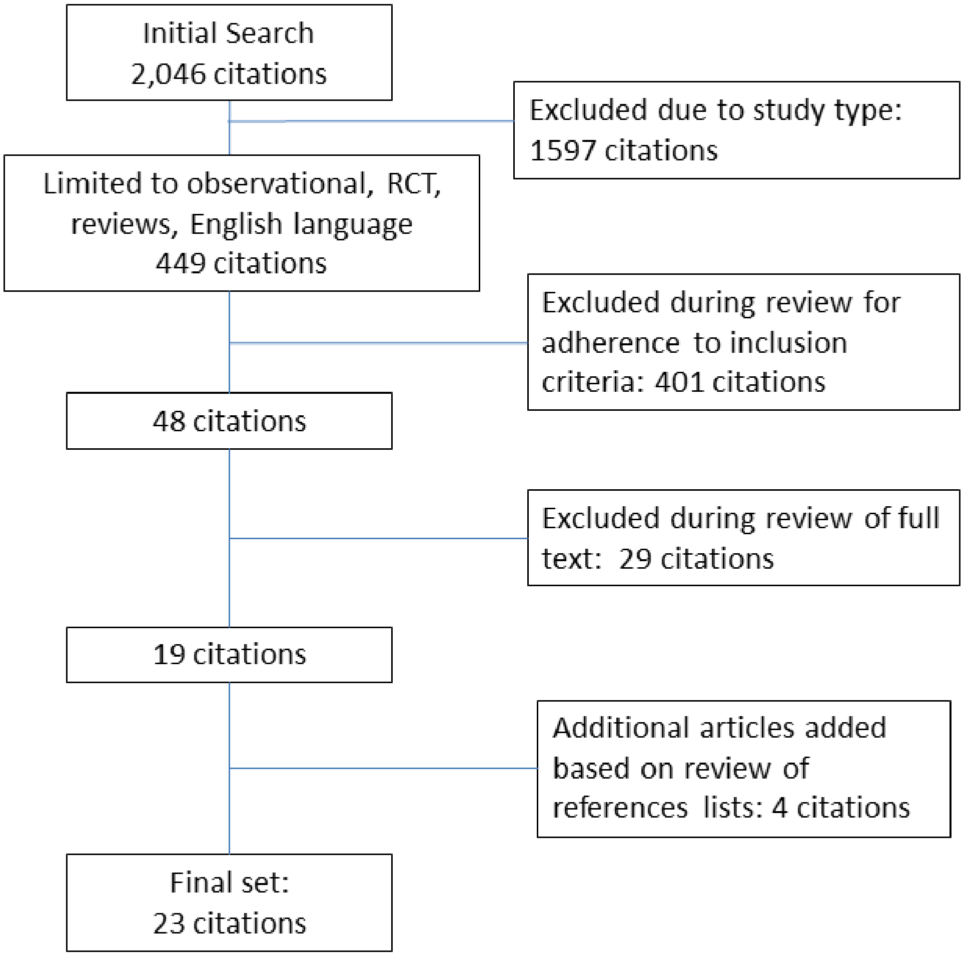
[1] Searches were constructed using the following example logic: Search ((((((((patient experience) OR satisfaction) AND cancer[Title/Abstract]) AND physician communication[Title/Abstract]) OR doctor communication[Title/Abstract]) OR patient-provider communication[Title/Abstract]) OR patient provider communication[Title/Abstract]) AND full text[sb] AND ("2001/01/01"[PDat] : "2015/07/01"[PDat]) AND Humans[Mesh] AND English[lang]) Filters:Systematic Reviews; Scientific Integrity Review; Review; Full text; Publication date from 2001/01/01 to 2015/07/01; Humans; English. Searches were then repeated using the search terms listed in Figure 1.

Articles were included if they explored an aspect of patient experience as a predictor or outcome variable and/or included patient-reported outcomes related to experiences with care in one of our five targeted domains (doctor communication, care coordination, access to care, patient perceptions of care quality, and other aspects of care, including prescription drug plan and customer service) In addition, while we recognize the distinction between satisfaction and experience, we chose to include studies of satisfaction when they focused on a specific aspect of patient care. Figure 2 shows the flow of articles through the selection process. Initial searches of the PubMed and CINAHL peer-reviewed literature databases resulted in 2,046 citations. After limiting to randomized trials, observational studies (including quantitative, qualitative, and mixed-methods studies), and reviews published in English, 449 citations remained.

A review and screening of titles and abstracts for adherence to inclusion criteria resulted in 48 citations. The vast majority were not included because they were not specific to cancer care. Two authors then independently reviewed the full text of the remaining articles, resulting in the exclusion of an additional 29 studies. Bibliographies of the articles in this subset (n=19) were then manually scanned to identify additional papers missed in previous literature searches, adding 4 studies. The inclusion of the final subset of 23 articles were confirmed by three authors to ensure adherence to inclusion criteria.

Data from the final set of studies were then abstracted and articles were categorized based on 5 areas of interest: (1) doctor/patient communication, (2) care coordination, (3) access to care, (4) patient perceptions of care quality, and (5) other aspects of patient experience. When studies spanned more than one category, we focused on the main outcome as stated in the study objective. Groupings of these articles were confirmed by an additional reviewer. The following data were extracted and summarized in table format: objective, design and methods, primary outcomes, results. Descriptive summary analysis and qualitative thematic analysis were performed to summarize and report the results. We then consulted with a collaborative group of experts (n=15) with experience in

Figure 2. Flow diagram of article selection



both SEER-linked data and patient experiences research to contextualize the findings.

Results

A total of 23 published articles met the inclusion criteria, including 1 randomized controlled trial, 11 observational studies, 6 reviews, and 5 qualitative or mixed methods studies. Table 1 summarizes the study objectives, sample characteristics, outcomes, and main findings for each included study.

Patient-Provider Communication

Four papers focused on communication between cancer patients and their healthcare providers: 1 review, 2 observational, and 1 qualitative study. Important factors contributing to effective patient-provider communication include clear and timely information, emotional support, and opportunities for shared decision-making [12]. Hack and colleagues [13] recorded and coded conversations between doctors and 172 newly diagnosed breast cancer patients, finding that doctors focused 88% of their communication on biomedical issues and that older patients and those with longer consultations reported the highest levels of satisfaction with communication. In addition, Baile and colleagues [12] reported in a narrative review of patient-provider communication in oncology that certain provider traits perceived by patients—friendliness, courtesy, empathy, and encouragement—increase patient satisfaction. In analyzing survey responses from 276 lung cancer patients, Nelson and colleagues [14] defined “inadequate provider communication” as occurring when providers discussed 5 or more (out of 11) topics "not at all" or "a little bit." The topics were symptom management, spiritual concerns, practical needs, identification of a proxy, living will preparation, prognosis, care goals, potential complications of therapy, life support preferences, and hospice referral. Overall, 52% of respondents reported inadequate provider communication, and almost 90% of stage III/IV patients reported that they received little to no information about hospice. Finally, a qualitative study by Mazor and colleagues [15] analyzed interviews with 137 people with cancer and their family members. The authors found that patients and family members were most aware of and sensitive to two functions of communication: information exchange, including the domains of content, timing, sufficiency, clarity, and accuracy; and fostering the relationship between provider and patient/family, including the dimensions of interpersonal manner, patient commitment, and knowing the patient. Overall, findings from patient-provider communication indicate that both comprehensive information exchange and patient provider relationship quality are important to patient experiences and their resultant health outcomes.

Care Coordination

Six studies identified in the review examined care coordination: 1 randomized trial, 2 observational studies, 1 systematic review (n=4), and 2 qualitative/mixed-methods studies. Many studies included multiple cancer types [16-19], one focused on breast cancer [20], and another on colorectal cancer [21]. Topics explored included perceptions of the critical components of care coordination [16, 18, 20] and the effectiveness of follow-up care delivery models, including nurse-led versus physician, and oncology versus primary care [17, 19, 21]. Identified facilitators of coordinated care included patient navigation, effective communication among treatment team providers, and providing sufficient and timely information to patients [16, 20]. Barriers reported as affecting a patient’s perception of care coordination included limited patient health literacy and obstructed access to the healthcare system [20]. Gaps in coordination in both visits with and communication between primary care providers and oncologists could result in delays in appropriate treatment and follow-up care [19]. In addition, two studies suggest that nurse-led follow-up care may be as effective in influencing patient experience as oncologist-led models [17, 21].

Access to Care

Three articles (1 systematic review and 2 randomized trials, focusing on breast and colorectal cancers) focused on factors associated with patient perceptions of access to care, including getting needed care, surveillance adherence, and timeliness of care receipt [22-24]. A prospective randomized trial assessing patient satisfaction with telephone follow-up versus hospital follow-up visits revealed no differences between the two modalities; however, scores for access to care items (getting care quickly, timeliness of care, and quality of care) were higher among patients receiving telephone follow-up calls vs. hospital follow-up [24]. Hendren and colleagues [23] found that racial and ethnic minority breast and colorectal cancer patients experience a higher number of social and instrumental barriers to receipt of care, ranging from communication to transportation, according to a study examining barriers to receiving care. Finally, a systematic review of 34 studies conducted by Carpentier and colleagues [22] assessing receipt of recommended surveillance and correlates of adherence among colorectal cancer survivors found large variation of both under and over utilization of recommended follow up care. The authors found that the majority of studies examined sociodemographic and disease/treatment factors, failing to investigate modifiable factors (i.e. system-level, patient experiences, psychosocial factors) and their influence on adherence to surveillance.

Patient Perceptions of Care Quality

Health Plan Quality: Nine papers that focused on patient perceptions of care quality were included in the review, including 5 observational studies and 4 literature reviews.

One notable study focused on associations between perceptions of care quality and survival for colorectal cancer patients [25], and found that patients reporting they were "completely satisfied" with their care demonstrated a significantly lower mortality, after controlling for clinical and sociodemographic characteristics. Four focused on quality of the health plan [26-29], and all investigated the variability of patient quality ratings across Medicare Advantage (MA) plans and subsequent impact on initial patient enrollment and changes in enrollment. A 2006 study assessed variations in care quality (based on Healthcare Effectiveness Data and Information Set (HEDIS) measures) across racial/ethnic groups, and determined that only 1 plan out of 151 assessed achieved both high quality and low disparity on more than 1 measure [26]. Another more recent study [28] examined associations between MA star ratings and plan enrollment and determined that an increase of 1 star was associated with 9.5% increase in likelihood to enroll. The authors also found that star ratings were less strongly associated with enrollment for black, rural, low-income, and younger beneficiaries. Xu and colleagues [29] investigated whether MA contract characteristics are associated with quality of care through star ratings and determined that nonprofit (vs. for-profit), larger, and older MA contracts were more likely to receive higher star ratings. An additional study assessed associations between MA plan attributes (cost, quality, and benefits) and beneficiary enrollment, finding that preference for higher quality and lower-cost MA plans with diminishing differences at higher star ratings of 4 and 5 [27].

Healthcare Provider Quality: A systematic review of 11 studies of patient perceptions of healthcare providers (specifically physicians) identified the constructs of loyalty, personal care, trust, and continuity as important guiding principles for assessing patient perceptions of provider quality. This review pointed toward the need for longitudinal research to further characterize the important attributes of patient-provider relationships. [30]. An additional systematic review of 44 studies of provider/institution-level factors and outcomes in ovarian cancer patients concluded that discipline and sub-specialization of primary treating physician conferred the biggest impact on survival and suggested improving trends in patient experience over time [31].

End-of-life Care Quality: Two papers focused on quality of end-of-life care are noteworthy. One study conducted within the Veteran's Health Administration determined key areas of quality that should be assessed: addressing patient well-being and dignity, providing adequate health information and communication; providing emotional and spiritual support; providing care around time of death, availing access to supportive services before the death, and providing access to benefits and services after the patient's death [32]. Finally, a narrative review identified referral to hospice within the last few days of life as a potential indicator of patient-perceived poor quality care [33].

Other Aspects of Patient Experience including Prescription Drug Plan and Customer Service

Our review did not identify studies exploring potential additional drivers of patient experience, such as healthcare customer service. One cross-sectional study did explore potential drivers of older adult patients' experience with prescription drug plans [34], looking at associations between the practice of prescribing and utilization of high risk medications and Medicare Part D CMS star ratings for composites including "Getting Needed Prescription Drugs," "Complaints about Drug Plan," "Rating of Drug Plan," and "Members Choosing to Leave the Plan." Medicare Star Ratings assess the performance of contracted health and drug plans on indicators of care access, clinical quality, member satisfaction, and customer service. Erickson and colleagues observed weak but significant associations between high-risk medications and "Getting Prescription Drugs," suggesting that high-risk medication usage is likely only one of many factors influencing overall member experience. The authors suggest that members may also place importance on perceived cost burdens when rating their prescription drug plans. It is also important to note that this study did not test for associations with actual utilization of prescription drug plans and subsequent health outcomes, a potential area for future research.

Summary and Implications from Scoping Review

We conducted this scoping review to identify gaps in the literature exploring specific factors related to patient experience in cancer care. Although a considerable amount of research has been done on patient experience, our review identified several important areas for future research. In general, there were few studies focusing on the associations between experience and outcomes including healthcare utilization, cost, adherence to guideline-concordant care, and patient health outcomes. As reimbursement models shift from pay for volume to pay for performance, there is increasing recognition of the importance of incorporating patient experiences in the definition of value [35]. It is essential to connect patient experiences with such outcomes to comprehensively define value.

Our analysis pointed to several important areas for future research, particularly in the areas of care coordination, patient-provider communication, and access to care. While the importance of effective patient-provider communication in cancer care is well-documented [36], our analysis indicated gaps in exploring drivers of cancer patient experiences with communication. In addition, future research could focus on the effects of communication on patient behaviors, and relationships between provider engagement, time spent, and patient behaviors.

There were few studies capturing cancer patient experiences with care coordination, particularly between oncologists and primary care providers, and specifically in medically underserved and rural patients. With an increasingly limited and overworked physician taskforce [37, 38], coordination between multiple types of healthcare providers, including midlevel providers, both during treatment and into survivorship is essential. Future research should focus on exploring the relationship between patient experiences with coordination and patient adherence to treatment, access, and cost of care. There is also great potential to explore patient experiences with models of follow-up care, as well as communication between providers.

Much of the previously published literature on perceived access to care focuses on access to follow-up after abnormal diagnostic results and subsequent survival. Gaps remain in our understanding of relationships between a patient's perceptions of access to care and adherence to cancer treatment and surveillance for recurrence and secondary cancers. Access to care has implications at all phases of the cancer care continuum, impacting outcomes from screening to diagnosis and treatment[39]. Further research is necessary to define the effect of access beyond initial treatment, including survivorship and palliative care. Our review also indicates a need for longitudinal research to further characterize the effects of patient-provider relationships on the quality of healthcare. Patients, particularly older adults, are being offered a growing number of healthcare plan choices, which further increases the importance for patient-perceived quality reporting and evaluation [40]. It is thus essential to investigate the effect of quality ratings on healthcare utilization. The role of health plan and care quality for underserved and vulnerable cancer patients also warrants further investigation.

Finally, there were few studies on other important aspects of patient experience, including healthcare customer service. Patients often face difficulties in completing paperwork and managing the administrative aspects of their care, including challenges in reaching their providers by telephone, unresponsiveness of office staff, and an increasing number of forms to fill out. These barriers can deter subsequent care-seeking and affect outcomes such as adherence to treatment and symptom reporting. We found no studies examining cancer patient experiences with provider and health plan customer service nor its relation to adherence through treatment and survivorship.

The results reported here are subject to certain limitations. First, the emphasis of the scoping review on concepts assessed by the CAHPS survey necessarily resulted in the exclusion of large subsets of the patient experience literature. In addition, this scoping review was limited to studies published in English since 2005, and focused on studies in North America.

New Research Resource to Examine Cancer Patient Experiences with Care: SEER-CAHPS

Overall, our review indicated that data resources are needed to explore both drivers and outcomes of patient experiences with cancer care. SEER-CAHPS is one such resource that could provide a great deal of information in each of these areas. The SEER-CAHPS linkage has been previously described by Chawla and colleagues [41]. We now present an updated report of the data resource and descriptive analyses, following the most recent linkage completed in 2015. Four principle data sources comprise the linked dataset: 1) CAHPS data for all Medicare Advantage (MA) and Fee for Service (FFS) beneficiaries between 1997 and 2013; 2) SEER data for CAHPS survey respondents with cancer living in a SEER-designated region and diagnosed between 1973-2011; 3) Medicare Enrollment Database demographic and eligibility data for all CAHPS survey respondents (1973-2011); and 4) Medicare claims data for all FFS beneficiaries who were CAHPS survey respondents (2002-2013). It is important to note that Medicare claims for 2002-2004 are only available for those who answered a survey in 2011 or prior. Medicare CAHPS survey items and composites can be used in research as both predictor and outcome variables in studies of patient experience among older adults with cancer. Linking CAHPS survey responses with SEER data and Medicare claims makes it possible to answer complex questions beyond traditional unlinked survey data. SEER-CAHPS has the potential to inform providers and consumers in several health topic areas, and Table 2 details potential future research questions in each domain.

Most importantly, this data resource provides a rich opportunity for analyses of Medicare beneficiaries' experiences with their care at various stages of the cancer care continuum, including: the initial year after diagnosis, when patients are most likely to receive cancer treatments; the years of immediate post-treatment follow-up care; those of long-term cancer survivorship; and the final end-of-life care phase. Table 3 shows demographic characteristics of CAHPS respondents residing in SEER areas from 1998-2013, and Table 4a and 4b indicate number of linked participants by time between first survey and diagnosis by cancer type for MA (2a) and FFS (2b) respondents, respectively, focusing on the most prevalent cancer types in the SEER-CAHPS linkage. It is important to note that the number of surveys is not equivalent to the number of individual beneficiaries, as approximately 10% of respondents were sent and answered the survey multiple times. For those with multiple surveys, only the first survey is analyzed. The most prevalent cancer types are prostate, breast, colorectal, and lung/bronchial. In total, the analytic file contains data from 4,467,618 Medicare beneficiaries, representing 231,089 surveys from patients with a cancer diagnosis, and 4,236,529 surveys from patients without a cancer diagnosis.

Although SEER-CAHPS can provide important insights into the experiences of care for patients with cancer, some limitations do exist. The data are limited to SEER registry areas, which represent approximately 30% of cancer cases in the U.S. (http://seer.cancer.gov/data/), as well as Medicare beneficiaries, including those over age 65 or eligible due to disability. Although some individuals have completed more than one survey, the linked resource was not designed for, and is not well-suited for, longitudinal survey analysis. As claims data are only available for FFS beneficiaries, sample size for analyses wishing to incorporate claims may be limited depending on cancer type. There is an adequate sample size for many types, however, as shown in Tables 4a and 4b. In addition, we acknowledge that data resources are not the only method to explore patient experiences. This resource, however, has a unique ability to answer questions using a population-based sample. Overall, SEER-CAHPS is a comprehensive source of information that provides the opportunity to link patient experiences with healthcare outcomes and compare individuals with and without cancer.

Summary

With increasing numbers of older adults living with cancer, receiving complex treatments, and dealing with complex and fragmented healthcare systems, studies of cancer patients' experiences are timely and imperative. This scoping review has highlighted key areas for future research on patient experiences, including key research questions that can be answered using a new linked data resource. SEER-CAHPS is a unique resource that can be used to understand cancer care delivery and the impact on patient outcomes at all phases of the cancer care trajectory. It also has the potential to assist healthcare systems and policy makers in improving the quality of care for Medicare beneficiaries with cancer.

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Table 1. Study characteristics and outcomes

Citation	Objective	Design and Methods	Primary Outcomes	Results
Patient-Provider Communication				
Baile, W.F. and J. Aaron, Patient-physician communication in oncology: past, present, and future. *Curr Opin Oncol*, 2005. 17(4): p. 331-5.	Highlight relevant studies on outcomes of communication with the cancer patient; discuss implications for training oncologists	Narrative Review	Measuring communication, foundation and benefits of communication, gaps in communication, barriers to effective communication, communicating change in prognosis, empowering patients, teaching and learning communication skills	Effective communication with cancer patient and family can influence desirable outcomes (including quality of life, satisfaction with care, and medical outcomes)
Hack, T.F., et al., Behind closed doors: systematic analysis of breast cancer consultation communication and predictors of satisfaction with communication. *Psychooncology*, 2010. 19(6): p. 626-36.	Explicate content of primary adjuvant treatment consultations in breast oncology, examine predictive relationships between patient and oncologist consultation factors and patient satisfaction with communication	Secondary descriptive study of women with breast cancer presenting for primary adjuvant treatment consultation who previously participated in prior communication	Coding of audiotapes using the Medical Interaction Processing System (MIPS); patient satisfaction with communication using Patient Perception Scale-assessing degree to which patient feels oncologist has adequately addressed the patient's disease concerns and been patient-focused during consultation	Biomedical content categories predominant in the consultations (88%), followed by administrative and psychosocial utterances; post-consultation satisfaction with communication was significantly higher for older patients, those with smaller primary tumors and those with longer consultation
Mazor, K.M., et al., Patients' and family members' views on patient-centered communication during cancer care. *Psychooncology*, 2013. 22(11): p. 2487-95.	Explore patients' and family members' views of communication during cancer care and identify aspects of patient-provider communication most important to patients and family members	Secondary data analysis of qualitative data of 137 patients with cancer and family members	qualitative (NA)	Patients want clinicians who provide information they need, when they need it, in a way they can understand; want physicians to listen and respond to questions and concerns; failure to provide information a patient needs could damage relationship and were integral to decision making, managing uncertainty

Nelson, J.E., et al., Patients rate physician communication about lung cancer. *Cancer*, 2011. 117(22): p. 5212-20.	Evaluate communication with lung cancer patients	Descriptive study of 276 lung cancer patients	Patient reported rating of physician communication on symptoms, spiritual concerns, practical needs, proxy appointment, living will prep, prognosis, care goals, potential complications of therapy, life support preferences, and hospice	Majority reported that physicians communicated not at all or a little bit, low ratings frequent for discussion of emotional symptoms, practical needs, spiritual concerns, proxy appointment, living will prep, life support preferences, and hospice; communication inadequate for patients of different ages, stages, and races
Care Coordination				
Arora, N.K., et al., Assessment of quality of cancer-related follow-up care from the cancer survivor's perspective. *J Clin Oncol,* 2011. 29(10): p. 1280-9.	Assess survivors' perceptions of different aspects of care in the last 12 months	Observational survey of 623 leukemia, bladder, colorectal cancer survivors diagnosed 2 to 5 years prior	Perceptions of different aspects of care, overall ratings of care	Delivery of quality follow-up care to cancer survivors may require efforts to improve patient-centered communication and coordination. Special emphasis needed on health promotion discussions and adoption of holistic care
Hawley, S., Janz, N., Lillie, S. et al. (2010). Perceptions of care coordination in a population-based sample of diverse breast cancer patients. *Patient Education and Counseling (81), Suppl: S34-40.*	Identify factors associated with perceptions of care coordination in diverse sample of breast cancer patients	Survey of 2268 breast cancer patients from SEER registries post diagnosis	Patient appraisal of care coordination during treatment experience; factors associated with care coordination	16.4% of women perceived low care coordination; 12.5% reported low satisfaction; race/ethnicity not significantly associated with care coordination; women with low health literacy 3-4 times likely to perceive low care coordination and low satisfaction with care coordination
Lewis, R., et al., Nurse-led vs. conventional physician-led follow-up for patients with cancer: systematic review. *J Adv Nurs*, 2009. 65(4): p. 706-23.	Evaluate effectiveness and cost-effectiveness of nurse-led follow-up for patients with cancer	Systematic review of (n=4) comparative studies and economic evaluations of nurse-led vs physician-led follow-up studies	Survival, recurrence, psychological morbidity; patient satisfaction, cost	Patients satisfied with nurse-led follow up; could consider patient-initiated or telephone follow-up to conventional care; more research needed

Shen, M.J., et al., A mixed-methods examination of communication between oncologists and primary care providers among primary care physicians in underserved communities. *Cancer*, 2015. 121(6): p. 908-15.	Explore PCP perceptions of communication with oncologists as well as PCP communication needs	Mixed methods-qualitative phase, interviewed 18 primary care providers practicing in underserved, minority communities; quantitative phase, online survey of 129 providers about preferences, experiences, and satisfaction with communication with oncologists	Qualitative: experiences with oncologists Quantitative: survey with questions on post-referral communication practices with oncologists; attitudes toward and preference for communication with oncologists	PCP-oncologist gap in communication occurred between diagnosis and treatment; PCPs wanted more communication with oncologists; wanted updates on patients' prognosis throughout treatment, and to be contacted via telephone or email
Walsh, J., et al., What is important in cancer care coordination? A qualitative investigation. *Eur J Cancer Care* (Engl), 2011. 20(2): p. 220-7.	Explore views and experiences of key stakeholders to identify the key components of cancer care coordination	Explorative descriptive qualitative study of 20 Cancer patients, 4 caregivers, 29 clinicians	Key components of care coordination in cancer	Organization of patient care, access to and navigation through healthcare system, allocation of 'key' contact person, effective communication and cooperation among multidisciplinary team and providers, delivery of services in complementary and timely manner
Young, J.M., et al., Multicenter randomized trial of centralized nurse-led telephone-based care coordination to improve outcomes after surgical resection for colorectal cancer: the CONNECT intervention. *J Clin Oncol*, 2013. 31(28): p. 3585-91.	Investigate effectiveness of a centralized, nurse-delivered telephone based service to improve care coordination and patient reported outcomes post colorectal cancer surgery	Two-arm parallel-group randomized trial of 756 patients undergoing surgery for primary colorectal cancer	FACT-C and Distress thermometer, questions about postop health services utilization; care coordination; Supportive Care Needs Survey Short Form, measuring unmet needs in domains: psychological, health system and info, physical and daily living, patient care and support, sexuality	Nurse-led follow-up may be as effective as oncologist in meeting patient needs; increases access

Access				
Carpentier, M.Y., et al., Receipt of recommended surveillance among colorectal cancer survivors: a systematic review. *J Cancer Surviv*, 2013. 7(3): p. 464-83.	Examine receipt of recommended post-treatment surveillance tests and procedures among CRC survivors, including adherence to established guidelines; identify correlates of CRC surveillance	Systematic review of 34 studies	Adherence, socio-demographic factors, patterns of association with adherence	Surveillance focused mainly on patient socio-demographic factors and disease/treatment characteristics; need for future work focusing on system- and provider-level issues, including patient experience, access to care, and care coordination among members of the oncology and PCP
Hendren, S., et al., Patients' barriers to receipt of cancer care, and factors associated with needing more assistance from a patient navigator. *J Natl Med Assoc*, 2011. 103(8): p. 701-10.	Understand patients' barriers to cancer care; determine which patients have a greater need for assistance from a patient navigator	Survey during randomized trial of 103 newly-diagnosed breast and colorectal cancer patients	Patient-reported barriers of care	Lack of social support, insurance/financial concerns, and problems communicating with health care providers. Barriers differed between non-minority and minority patients, and minority patients faced a greater number of barriers
Kimman, M.L., et al., Patient satisfaction with nurse-led telephone follow-up after curative treatment for breast cancer. *BMC Cancer*, 2010. 10: p. 174.	Explore patient satisfaction; investigate cost-effectiveness of several follow-up strategies in first year after breast cancer treatment	Patient satisfaction among 299 breast cancer patients post treatment who were participants of RCT	Ware's Patient Satisfaction Questionnaire (PSQ III)	Nurse-led telephone follow-up care significantly higher for patient satisfaction with access to care. Nurse-led follow-up care may be acceptable alternative to traditional hospital follow-up
Quality of Care				
du Bois, A., et al., Variations in institutional infrastructure, physician specialization and experience, and outcome in ovarian cancer: a systematic review. *Gynecol Oncol*, 2009. 112(2): p. 422-36.	Summarize available data evaluating impact of different physician and hospital characteristics on outcomes in ovarian cancer patients	Systematic review 44 studies assessing relationship between physician and/or hospital specialty or volume and at least one outcome of interest	Survival (Surgical outcome, completeness of staging, patient experience)	Discipline and sub-specialization of primary treating physician most important for survival; showed some improvement in patient experience over time

Earle, C.C., et al., Aggressiveness of cancer care near the end of life: is it a quality-of-care issue? *J Clin Oncol*, 2008. 26(23): p. 3860-6.	Review literature and update analyses to the aggressiveness of cancer care near the end of life	Narrative review	Trends and predictors of aggressive cancer care (chemo near death and underutilization of hospice services)	High proportion of patients never referred to hospice, or referred only in last few days of life may indicate poor-quality care
Finlay, E., S. Shreve, and D. Casarett, Nationwide Veterans Affairs quality measure for cancer: the family assessment of treatment at end of life. *J Clin Oncol*, 2008. 26(23): p. 3838-44.	Describe national initiative to measure quality of care at end of life (FATE-Family assessment of treatment at end of life)	Descriptive study of quality initiative with surrogates for 262 deceased cancer patients	FATE: reflects key areas of palliative care-patient's well-being and dignity, adequacy of information and communication, emotional and spiritual support, care around time of death, access to services before the death, access to benefits and services after the patient's death	Higher satisfaction of care associated with palliative care consultation, hospice referral, and having a DNR at time of death. Lower satisfaction scores associated with ICU death
Reid, R.O., et al., Association between Medicare Advantage plan star ratings and enrollment. *JAMA*, 2013. 309(3): p. 267-74.	Assess association between Medicare Advantage plan quality ratings and enrollment	Cross-sectional study of 2011 Medicare Advantage (MA) enrollments among 952,352 first-time enrollees and 322,699 enrollees switching plans	Likelihood to enroll and star ratings	1-star higher rating associated with 9.5 percentage-point increase in likelihood to enroll; highest rating associated with 1.9 percentage point increase in likelihood to enroll; star ratings less strongly associated with enrollment for black, rural, low-income, and youngest beneficiaries
Reid, R.O., et al., The Roles of Cost and Quality Information in Medicare Advantage Plan Enrollment Decisions: An Observational Study. *J Gen Intern Med*, 2015.	Assess associations between MA plan attributes (cost, quality, and benefits), brand market share, and beneficiary's enrollment decisions	Cross-sectional study of 84,7069 beneficiaries enrolling in Medicare Advantage for the first time in 2011	Plan attributes and enrollment; willingness to pay for quality	Beneficiaries prefer higher quality and lower-cost MA plans, but marginal utility for quality diminishes at higher star ratings

Ridd, M., et al., The patient-doctor relationship: a synthesis of the qualitative literature on patients' perspectives. *Br J Gen Pract*, 2009. 59(561): p. e116-33.	Derive conceptual framework of factors that define patient-doctor relationships from patient perspective	Systematic review and synthesis of qualitative literature of 11 studies	Patient-doctor relationship aspects	Studies explored patient-doctor relationship generally, or specifically in loyalty, personal care, trust, and continuity; longitudinal care and patient experiences important; future research needed on associations between longitudinal care, patient experiences, and depth of patient-provider relationship
Trivedi, A.N., et al., Relationship between quality of care and racial disparities in Medicare health plans. *JAMA*, 2006. 296(16): p. 1998-2004.	Assess variations among Medicare health plans in overall quality and racial disparity in HEDIS measures, to determine whether high-performing plans exhibit smaller racial disparities; identify plans with high quality and low disparity	Analysis of 43,1573 observations in 151 Medicare health plans from 2002 to 2004; regression of relationship between quality and racial disparity	Hemoglobin A1C for enrollees with diabetes; blood pressure for those with HTN, cholesterol level for enrollees with diabetes post coronary event	Clinical performance on HEDIS measures lower for Black enrollees than White; health plans varied substantially in overall quality and racial disparity on each of the 4 outcome measures; only 1 health plan achieved both high quality and low disparity on more than 1 measure
Xu, P., et al., Relationships between Medicare Advantage contract characteristics and quality-of-care ratings: an observational analysis of Medicare Advantage star ratings. *Ann Intern Med*, 2015. 162(5): p. 353-8.	Investigate whether MA contract characteristics are associated with quality of care through Medicare star ratings	Retrospective study of MA star ratings in 2010 on 409 Medicare Advantage contracts	Star ratings, plan characteristics (contract enrollment numbers, contract maturity, contract type, operating area)	Nonprofit, larger, and older MA contracts more likely to receive higher star ratings; nonprofit MA contracts received significantly higher star ratings than for-profit contracts
Other Aspects				
Erickson, S.C., R.S. Leslie, and B.V. Patel, Is there an association between the high-risk medication star ratings and member experience CMS star ratings measures? *J Manag Care Spec Pharm*, 2014. 20(11): p. 1129-36.	Determine if high-risk medication star ratings are associated with member experience CMS star ratings	Cross-sectional analysis of 443 Medicare contracts for MA-prescription drug plan	Star scores for "Getting Needed Prescription Drugs", "Rating of Drug Plan", and "Members Choosing to Leave the Plan"	Weak positive associations between high-risk medication scores and member experience measures; getting needed prescription drugs most highly associated with member ratings

Table 2. Sample Research Questions using SEER-CAHPS data*

Patient Experience • How have patient experiences among older cancer patients changed over time? • How do the experiences of cancer patients with multiple chronic conditions compare to individuals without cancer or with no comorbidities? • Do cancer patient experiences predict mortality and survival? • How do cancer patient experiences vary across socio-demographic groups? • Are there regional, geographic, and/or health plan effects on cancer patient experiences of care?
Patient/Provider Communication • Do cancer patient experiences with communications predict survival? • How do perceptions of experiences of care vary between cancer types? • Does higher perceived quality patient/provider communication predict different healthcare utilization patterns among cancer survivors?
Care Coordination • Does perception of care coordination predict adherence to follow-up care in cancer survivors? • Does perception of care coordination vary based on cancer phase (post diagnosis, treatment, in last year of life)? • Does perception of care coordination vary by cancer treatment modality?
Access to Care • Is perceived access to care associated with time between diagnosis and first course of cancer treatment? • Do patient experiences with care mediate the association between race/ethnicity and survival across cancer types? • Does type of healthcare provider seen predict perceived timeliness of care for cancer patients?
Patient Perceptions of Care Quality • Do cancer patient experiences with quality predict subsequent healthcare utilization? • Does perceived quality of provider vary by cancer type?
Other Aspects of Patient Experience • Do experiences with prescription drug plan predict adherence to cancer treatment? • Do experiences with getting prescription drugs predict overall survival for cancer patients? • Do cancer patient experiences with customer service vary across urban and rural settings?

*Analyses of some of these topics may require additional linkages by investigators. In addition, availability of data to answer given research questions varies across cancer sites and years of diagnosis.

Table 3. Demographic characteristics of CAHPS respondents residing in SEER areas by program type: 1997–2013

	Cancer (n=205,339)					Non-cancer (n=724,965)				
Demographics	Total	MA		FFS		Total	MA		FFS	
		N	%	*N*	%		*N*	%	*N*	%
Total	205,339	124,668	60.7	80,671	39.3	724,965	444,740	61.3	280,225	38.7
Age										
Under 65	11,222	5,811	4.7	5,411	6.7	80,087	41,947	9.4	38,140	13.6
65–74	97,047	61,054	49.0	35,993	44.6	350,214	221,501	49.8	128,713	46.0
75–84	75,652	45,815	36.7	29,837	37.0	224,358	140,951	31.7	83,407	29.8
85+	21,418	11,988	9.6	9,430	11.7	70,306	40,341	9.0	29,965	10.7
Gender										
Male	101,819	61,754	49.5	40,065	49.7	297,013	180,489	40.6	116,524	41.6
Female	103,520	62,914	50.5	40,606	50.3	427,953	264,251	59.4	163,701	58.4
Race/ethnicity										
White	153,310	90,417	72.5	62,893	78.0	496,331	294,331	66.2	202,128	72.1
Black	13,179	8,404	6.7	4,775	5.9	49,457	31,857	7.2	17,600	6.3
Other	1,426	1,040	0.8	386	0.5	5,228	3,828	0.9	1,400	0.5
Asian	9,343	6,461	5.2	2,882	3.6	44,013	29,675	6.7	14,338	5.1
Hispanic	12,467	8,969	7.2	3,498	4.3	69,405	48,785	11.0	20,621	7.4
North American Native	674	389	0.3	285	0.4	3,323	1,718	0.4	1,605	0.6
Mixed, non-Hispanic	3,286	1,926	1.5	1,360	1.7	13,454	1,802	1.8	5,672	2.0
Unknown	11,654	7,062	5.7	4,592	5.7	43,734	26,872	6.0	16,862	6.0
Education										
Did Not Complete High School	42,345	27,152	21.8	15,193	18.8	161,102	104,420	23.5	56,682	20.2
High School Graduate or GED	60,878	37,403	30.0	23,475	29.1	214,932	132,692	29.8	82,240	29.4

Some College/2-years Degree	46,722	28,856	23.1	17,866	22.1	167,215	103,200	23.2	64,015	22.8
4-years College Graduate	19,159	10,824	8.7	8,335	10.3	61,018	35,119	7.9	25,899	9.2
More than 4-years College Degree	23,653	12,740	10.2	10,913	13.5	74,309	40,162	9.0	34,147	12.2
Unknown	12,582	7,693	6.2	4,889	6.1	46,389	29,147	6.6	17,242	6.2
Health characteristics-smoking										
Non Smoker or Former Smoker	171,882	103,834	83.3	68,048	84.4	608,943	374,549	84.2	234,394	83.6
Current Smoker	21,941	13,772	11.0	8,169	10.1	74,423	44,175	9.9	30,248	10.8
Unknown	11,516	7,062	5.7	4,454	5.5	41,599	26,016	5.9	15,583	5.6
Spanish survey										
English	190,352	115,842	92.9	74,510	92.4	673,121	412,434	92.7	260,687	93.0
Spanish	1,529	1,037	0.8	492	0.6	11,737	7,839	1.8	3,898	1.4
None/ Unknown	13,458	7,789	6.2	5,669	7.0	40,107	24,467	5.5	15,640	5.6
Proxy status										
Proxy	22,086	12,244	9.8	9,842	12.2	89,418	51,399	11.6	38,019	13.6
No Proxy	155,394	98,371	78.9	57,023	70.7	524,107	336,071	75.6	188,036	67.1
Unknown	27,859	14,053	11.3	13,806	17.1	111,440	57,270	12.9	54,170	19.3
General health status										
Excellent	14,040	9,093	7.3	4,947	6.1	60,697	38,833	8.7	21,864	7.8
Very Good	48,929	30,570	24.5	18,359	22.8	180,799	122,755	25.4	68,024	24.3
Good	74,469	46,115	37.0	28,354	35.1	248,570	156,403	35.2	92,167	32.9
Fair	47,614	27,920	22.4	19,694	24.4	160,983	96,059	21.6	64,924	23.2
Poor	13,252	6,694	5.4	6,558	8.1	47,258	24,143	5.4	23,115	8.3
Unknown	7,035	4,276	3.4	2,759	3.4	26,658	16,527	3.7	10,131	3.6

Table 4a. Number of SEER-CAHPS respondents by first cancer site and date of diagnosis: Managed Care (no claims data available)

First cancer	Total number of SEER linked patients	First survey before month of first cancer diagnosis			First survey within 2 years of first cancer diagnosis			First survey within 3–5 years of first cancer diagnosis			First survey within 6–10 years of first cancer diagnosis			First survey within 11+ years of first cancer diagnosis	
		N	%		*N*	%		*N*	%		*N*	%		*N*	%
Prostate	24,551	8,114	33.0		4,076	16.6		4,059	16.5		5,165	21.0		3,137	12.8
Breast	22,668	7,110	31.4		3,216	14.2		2,939	13.0		4,158	18.3		5,245	23.1
Colorectal	13,538	6,057	44.7		1,896	14.0		1,556	11.5		1,903	14.1		2,126	15.7
Lung and Bronchial	11,617	8,917	76.8		1,331	11.5		567	4.9		467	4.0		335	2.9
Ovary	1,414	686	48.5		174	12.3		109	7.7		142	10.0		303	21.4
Uterine Corpus	3,901	1,037	26.6		463	11.9		431	11.0		653	16.7		1,317	33.8
Uterine Cervix	1,583	128	8.1		30	1.9		67	4.2		134	8.5		1,224	77.3
Bladder	6,298	3,037	48.2		915	14.5		717	11.4		804	12.8		825	13.1
Melanoma	6,962	2,863	41.1		990	14.2		946	13.6		1,034	14.9		1,129	16.2
Head and Neck	6,358	2,954	46.5		883	13.9		727	11.4		801	12.6		993	15.6
Kidney and Renal Pelvis	2,877	1,427	49.6		417	14.5		364	12.7		350	12.2		319	11.1
Non-Hodgkin Lymphomas	4,271	2,294	53.7		580	13.6		474	11.1		492	11.5		431	10.1
Leukemia	2,379	1,497	62.9		303	12.7		215	9.0		211	8.9		153	6.4
Stomach	1,414	931	65.8		196	13.9		81	5.7		101	7.1		105	7.4
Esophagus	739	561	75.9		80	10.8		48	6.5		33	4.5		17	2.3
Pancreas	2,019	1,835	90.9		112	5.5		35	1.7		20	1.0		17	0.8
Liver and Intrahepatic Bile Duct	924	768	83.1		91	9.8		38	4.1		19	2.1		8	0.9
Simultaneous cancers*	1,758	1,004	57.1		232	13.2		161	9.2		193	11.0		168	9.6
Other	9,397	5,907	62.9		1,141	12.1		781	8.3		739	7.9		829	8.8

Table 4b. Number of SEER-CAHPS respondents by first cancer site and date of diagnosis: Fee-for-Service (claims data available)

	Total number of SEER linked patients	First survey before month of first cancer diagnosis		First survey within 2 years of first cancer diagnosis		First survey within 3–5 years of first cancer diagnosis		First survey within 6–10 years of first cancer diagnosis		First survey within 11+ years of first cancer diagnosis	
		N	%	*N*	%	*N*	%	*N*	%	*N*	%
Prostate	16,464	3,746	22.8	2,795	17.0	3,078	18.7	4,103	24.9	2,742	16.7
Breast	15,440	3,429	22.2	2,104	13.6	2,457	15.9	3,349	21.7	4,101	26.6
Colorectal	8,195	2,543	31.0	1,350	16.5	1,237	15.1	1,532	18.7	1,533	18.7
Lung and Bronchial	6,420	4,142	64.5	992	15.5	550	8.6	474	7.4	262	4.1
Ovary	919	307	33.4	138	15.0	108	11.8	134	14.6	232	25.2
Uterine Corpus	2,753	540	19.6	349	12.7	346	12.6	526	19.1	992	36.0
Uterine Cervix	1,020	56	5.5	32	3.1	36	3.5	85	8.3	811	79.5
Bladder	3,992	1,363	34.1	680	17.0	628	15.7	706	17.7	615	15.4
Melanoma	5,134	1,371	26.7	848	16.5	854	16.6	1,009	19.7	1,052	20.5
Head and Neck	4,530	1,600	35.3	713	15.7	717	15.8	717	15.8	783	17.3
Kidney and Renal Pelvis	1,964	745	37.9	330	16.8	290	14.8	347	17.7	252	12.8
Non-Hodgkin Lymphomas	2,773	1,030	37.1	470	16.9	444	16.0	468	16.9	361	13.0
Leukemia	1,596	714	44.7	253	15.9	214	13.4	253	15.9	162	10.2
Stomach	759	415	54.7	111	14.6	74	9.7	95	12.5	64	8.4
Esophagus	420	261	62.1	65	15.5	36	8.6	36	8.6	22	5.2
Pancreas	1,007	828	82.2	107	10.6	34	3.4	23	2.3	15	1.5
Liver and Intrahepatic Bile Duct	470	337	71.7	64	13.6	39	8.3	22	4.7	-	-
Simultaneous cancers*	1,078	436	40.4	198	18.4	156	14.5	161	14.9	127	11.8
Other	5,737	2,734	47.7	904	15.8	726	12.7	690	12.0	683	11.9